
Meeting the Needs of People with AIDS: Local Initiatives and Federal Support

DAVID N. SUNDWALL, MD
DOROTHY BAILEY

Dr. Sundwall has been Administrator of the Health Resources and Services Administration and an Assistant Surgeon General in the Public Health Service's Commissioned Corps since August 1986. He had previously served for 5 years as physician advisor to the majority staff of the U.S. Senate Committee on Labor and Human Resources.

Ms. Bailey is Chief of the Information Resources Branch, Division of Resources Analysis and Information, Office of Special Projects, Bureau of Maternal and Child Health and Resources Development, Health Resources and Services Administration.

Tearsheet requests to Ms. Bailey, Rm. 11A-10, Parklawn Bldg, 5600 Fishers Lane, Rockville, MD 20857

Synopsis

The Health Resources and Services Administration (HRSA), one of the seven agencies of the Public Health Service, is working to meet some of the resource and patient service needs engendered by the epidemic of acquired immune deficiency syndrome (AIDS). Those actions derived from, and support the continuation, expansion, and

replication of, initiatives at the community and State levels.

HRSA is carrying out many of the recommendations of the Intragovernmental Task Force on AIDS Health Care Delivery by enhancing the AIDS training of health care personnel in prevention, diagnosis, and care and by counseling and encouraging the expansion of facilities outside hospitals to care for AIDS patients. The agency, through its pediatric AIDS demonstration projects, is working on models for the care of children with HIV infections.

The needs of AIDS patients are being addressed through a drug therapy reimbursement program; demonstration grants to 13 projects to promote coordinated, integrated systems of care in the community; and grants for the development of intermediate and long-term care facilities for patients.

Ten regional education and training centers, funded in 1987 and 1988, will increase the supply of health care providers prepared to diagnose and treat persons with HIV infections. Programs will be conducted for several thousand providers over the next 3 years, using such modalities as televised programs and train-the-trainer courses. The centers will also offer support and referral services for providers.

SEVEN YEARS AGO, AN UNUSUAL immune dysfunction was first identified in a few homosexual men. That condition, designated the acquired immunodeficiency syndrome, or AIDS, has spread to become an epidemic of major proportions. Epidemiologists soon learned that the syndrome was caused by a transmissible agent. A massive research effort identified the agent as a retrovirus, now known as the human immunodeficiency virus, or HIV. Sexual transmission among homosexual men and bloodborne transmission among intravenous drug users are the most common ways of contracting the virus. As of early 1988, more than 50,000 Americans with an AIDS diagnosis had been reported to the Centers for Disease Control, Public Health Service; more than 29,000 of those persons have died. Those diagnosed with AIDS represent only a fraction of the estimated 1.5

million Americans who may be infected with the virus. HIV infection manifests in a spectrum of diseases, with AIDS being the most severe end-stage form.

The Public Health Service (PHS) projects that by 1991, short of major breakthroughs in therapeutics, a cumulative 324,000 AIDS cases will be reported in the United States, and more than 179,000 of these people will have died. Providing the spectrum of services needed by persons with HIV infections will have an enormous impact on our health and medical care systems. One estimate, for example, graphically demonstrates the effect of the epidemic on health resources: by 1991, 12,831 U.S. hospital beds will be occupied by AIDS patients, outnumbering the beds occupied by lung cancer patients or automobile accident victims (1).

The resulting stress on our health resources, our

'Many of these babies are abandoned, yet there are very few foster care arrangements for these dying children. As a consequence, hospital staff become not only primary care providers but also the only source of hugs and love that these children will know.'

health care providers, and our budgets underscores the gaps in the present system. Many gaps have been identified from the experiences of those already performing herculean tasks in caring for HIV-infected patients in local communities.

The approaches taken in these communities have varied in response to the numbers of patients but, more particularly, to the characteristics of the infected population. For example, AIDS patients who are IV drug abusers have no organized advocacy groups, and hospitals must be relied on to provide care for their acute illnesses, as in New York City. Conversely, an infected population of homosexual males who have a well-established political and social advocacy structure, as in San Francisco, has created a spectrum of services given in care settings ranging from residential to acute.

Nevertheless, some common needs have been identified as critical. One of the most important is to coordinate all sectors of the medical and social care systems in the provision of care and in planning to meet future needs. Patients should have an array of care sites, ranging from private home to hospice. Compassionate care requires counseling for the patient, family, and friends that may include financial and legal advice, education about AIDS and its prevention, and bereavement support. Various kinds of care providers who work in case management teams are needed. They should have access to the latest clinical findings and referral and information support. Only through such support can we alleviate the stress placed on health care providers as they struggle to treat so many terminally ill, often young, patients, while they face their own concerns about contagion.

It is the purpose of this paper to discuss those community-articulated needs within the context of the initiatives supported by the Health Resources

and Services Administration (HRSA), one of the seven agencies of the PHS. HRSA and its three Bureaus administer a number of programs serving the health professions, health delivery, and health resources needs of the nation. The major AIDS initiatives in HRSA are the responsibility of the Office of Special Projects, located in the Bureau of Maternal and Child Health and Resources Development (BMCHRD). However, HRSA programs and Bureaus deal with AIDS in three primary areas: planning and coordination, patient needs, and provider education.

Planning and Coordination

Early in 1987, the Intragovernmental Task Force on AIDS Health Care Delivery was organized at the request of Robert E. Windom, MD, Assistant Secretary for Health, Department of Health and Human Services (DHHS). The task force, chaired by HRSA Administrator Dr. David Sundwall, included representatives from a cross-section of DHHS and from the Departments of Defense, State, and Housing and Urban Development, as well as the Veterans Administration.

The task force's charge was to examine the issues related to the care of people with HIV infection. These included access to care, quality of care, financing of care, integration of government activities at all levels, and the role of the family. Over a period of 8 months, the task force held 10 meetings, collecting expert testimony and information from private organizations and foundations, health care providers, State officials, and patient representatives. These people and organizations already had a wealth of experience and knowledge in the day-to-day care of HIV-infected people, and they helped the task force to understand the medical, epidemiologic, psychosocial, and cultural aspects of the AIDS epidemic.

The final task force report, released January 6, 1988, by Dr. Windom, cited 17 recommendations for improving the delivery of care and the use of resources in our efforts against the AIDS epidemic (2). Rather than listing each recommendation, we highlight these three on which HRSA is presently acting.

- Improve the education of health professionals in the diagnosis, care, and counseling of HIV-infected individuals,
- Enhance AIDS training of health personnel in federally supported health facilities, and
- Encourage expansion of intermediate and long-

term care facilities devoted to care of AIDS patients.

In addition, we will discuss several other task force recommendations that relate to finding new approaches to problems such as caring for intravenous drug abusers and recognizing and treating the mental health needs of AIDS and other HIV-infected patients. HRSA collaborates with other PHS agencies in finding solutions to such problems. The demonstration projects already funded by HRSA which we expect to help in these endeavors will be described subsequently.

An overriding concern, which should be addressed as a subset of every recommendation, is the disproportionate share of members of minority groups among AIDS- and HIV-infected people. As the task force report states, "While Blacks and Hispanics, respectively, comprise 12 percent and 7 percent of the United States population, 24 percent of adults and children with AIDS are Black and 14 percent are Hispanic."

Related to the work of the task force are the issues surrounding pediatric AIDS. The statistics are alarming. By 1991, it is estimated that more than 3,000 children will have contracted AIDS, most through birth by an infected mother, and most will have died. More than 50 percent of these babies will be black; another 25 percent, Hispanic. Many of these babies are abandoned, yet there are very few foster care arrangements for these dying children. As a consequence, hospital staff become not only primary care providers, but also the only source of hugs and love that these children will know.

The issues surrounding this tragic population were discussed at the April 1987 Surgeon General's Workshop on Children with HIV Infection and Their Families. The workshop's participants made a number of recommendations; one group of these relates to the work of this Agency (3a). The work group focusing on development of a model for health care for children with HIV infection specified that access to needed services should be increased for both HIV-infected children and their families and that programs of care should be tailored to regional needs.

Recognizing a need to prepare for health professions education in AIDS, HRSA sponsored a series of discipline-specific work group meetings and a conference in November 1987. Co-sponsored by the Bureau of Health Professions and the BMCHRD, the conference identified issues and proposed educational objectives on HIV and AIDS

curriculums and training. These recommendations and discussions, specific to medicine, dentistry, nursing, social services, physician assistants, emergency medical personnel, and public health professions, will be published later in 1988.

Patient Needs

Improved access to services for all HIV-infected populations is one of the many patient care needs which HRSA is addressing through a series of grant programs. These programs are designed to assist low-income AIDS patients who need help in paying for certain therapeutic drugs, to develop coordinated systems of medical and support services for HIV-infected persons, to demonstrate effective care for pediatric AIDS patients, and to support development of nonacute care resources which can provide more appropriate and less costly care than that given in hospitals.

AIDS drug reimbursement program. This 1-year program provided a total of \$30 million to the States and Territories to reimburse for drugs approved by the Food and Drug Administration as life-prolonging for AIDS patients. Congress made this appropriation in response to the needs of low-income AIDS patients who were unable to purchase the newly approved drug zidovudine (AZT). AZT appears to prolong the life of some AIDS patients, and it is the only drug so proven.

As of November 2, 1987, grants had been awarded to all 50 States in amounts based on the percentage of all U.S. AIDS patients living in the State as of July 2, 1987. This targeting resulted in 71 percent of the grant funds (about \$21.1 million) going to those five States with the highest numbers of persons with AIDS: New York, California, Texas, Florida, and New Jersey.

HRSA will review State reports on the use of these funds and, as appropriate, redistribute any remaining funds from areas of low demand to those with greater needs.

The AIDS service demonstration grants. The critical challenge in caring for AIDS patients is to coordinate medical and related services into a *system* of care. As we pointed out earlier, HRSA staff know that many communities have already taken steps toward structuring such systems. Therefore, these demonstration grants were designed to support and strengthen such efforts.

In September 1986, HRSA awarded \$15.3 million in grants to the four metropolitan areas with

the greatest number of AIDS patients at that time: New York City; Miami, FL; and San Francisco and Los Angeles, CA. In 1987, an additional \$10 million was awarded to provide supplemental funding to the first four projects and to support nine new projects located in Washington, DC; Newark, NJ; Atlanta, GA; Boston, MA; Fort Lauderdale and Palm Beach County, FL; Seattle, WA; and San Diego and Orange County, CA.

Service demonstration grants support communities in their efforts to

- Identify unmet service needs and take steps to meet those needs;
- Provide optimal integration of community resources through effective coordination;
- Ensure continuity of services through effective case management; and
- Reduce the overall cost of providing medical services for AIDS patients by providing alternatives to hospital care.

The spectrum of services to be developed by the grants include preventive as well as treatment and support services for the patients, their families, and friends. We are interested in how these communities will link service and administrative components, and we will examine the success of these grants in the context of those linkages. Service and administrative components of all the demonstration projects are the following:

- ambulatory care, such as counseling, psychosocial support, and diagnostic services;
- residential or in-home care which may embrace long-term care facilities, hospice services, and home health services;
- case management services;
- linkages with hospital care;
- nonmedical support services, such as running errands or shopping and cleaning for nonambulatory AIDS patients;
- pediatric services, where there is such need; and
- integration of services to avoid the need for a separate system of care for AIDS patients. The means of integration may include area advisory committees and links with other AIDS programs or foundations at national, State, and local levels.

After 1 year of operation, grantees already report accomplishments achieved through effective coalitions of community services and providers.

In Miami, for the first time homeless children with AIDS have been placed in foster homes

through a contract with the Children's Home Society. Before, these children were in custodial care at Jackson Memorial Hospital.

In New York, the grantee subcontracted with AIDS Resource Center to operate Bailey House, a supervised group residence for 44 homeless persons with AIDS who were too well for hospitalization.

In San Francisco, mental health needs of persons with AIDS are being met through a program of volunteer private practice therapists who provide psychotherapy free or at reduced rates.

Finally, in Los Angeles, a case-management prototype is being developed and an organized outreach and AIDS education counseling service is being offered for the first time in minority communities.

Pediatric AIDS health care demonstrations. As of January 18, 1988, 778 children with AIDS had been reported to the CDC. Earlier, we noted the predictions of dramatic increases in this population by 1991. The tragedy is larger than these data portray. As many as 2,000 other children had symptoms of HIV infection in 1987, though they were not reported as AIDS cases (3b). And these children also require services.

Two HRSA programs are structured to help meet these needs. Nine of the 13 demonstration grants described previously target the development of AIDS services for children as one of the populations in need. In addition, \$5 million was appropriated late in 1987 to support pediatric AIDS demonstration grants, to be awarded in 1988 by HRSA's Bureau of Maternal and Child Health and Resources Development. These grants will help communities to develop service resources, strategies, and models to supply prevention services and care to at-risk women and their children.

Expansion of nonacute care facilities for AIDS patients. In line with the Intragovernmental Task Force's recommendations on the need for nonacute care resources, HRSA is preparing to manage a \$6.7 million grant program that will support the renovation and construction of intermediate and long-term care facilities for AIDS patients. The grants should be useful in helping communities to meet the acute shortage of alternatives to hospitalization.

Provider Needs

Education and training centers. Just as a number of events gave rise to the HRSA initiatives in

support services for AIDS patients, the rapidly developing epidemic has created critical needs among health care providers which we are meeting through grants to establish regional Education and Training Centers (ETCs).

Initially, AIDS patients were concentrated in several metropolitan areas and received treatment in hospital settings provided by medical specialists who eventually became known as AIDS specialists. This trend continues to some extent; in high prevalence areas, relatively few physicians are caring for the majority of AIDS patients. Even in nonacute care settings, other health professionals who can serve the multiple needs of AIDS patients are in short supply. Other changes in the AIDS epidemic include the spread of the disease from urban locales to suburban and even rural areas. This spread, and the increasing numbers of AIDS and HIV-related cases, translate into a need for more providers and more training for health professionals. In addition to these training needs, practicing professionals will require information and referral resources as well as support in providing counseling and health education concerning prevention in their communities.

To meet this critical need for primary care providers capable of treating AIDS patients, HRSA awarded \$1.9 million in 1987 to fund four ETCs. These centers will serve 16 States, Puerto Rico, and the Virgin Islands; they are located at New York University in New York City, University of California at Davis, University of Washington in Seattle, and Ohio State University in Columbus. In March 1988, \$5.2 million was awarded to seven additional centers that will serve populations in a total of 31 States and the District of Columbia. These centers are located at Emory University in Atlanta, GA, Louisiana State University in New Orleans, University of Colorado at Denver, University of Illinois at Chicago, University of Maryland at Baltimore, University of Massachusetts in Worcester, and the University of Southern California in Los Angeles.

The ETC grants are awarded to institutions or consortia of institutions that demonstrate an ability to conduct high-quality training programs for a large number of health care professionals. The first four ETCs anticipate that they will train several thousand health professionals over a 3-year span. Such modalities as televised training and "train-the-trainer" programs will be used to maximize the available resources.

Through this network of coordinated regional centers, we plan to meet a number of objectives

The 600 community and migrant health centers supported by HRSA grants provide services to more than 5.5 million low-income, underserved people. As the AIDS epidemic moves from urban areas, we expect that these centers will become an even more valuable resource of primary medical and preventive care.

which support task force recommendations and the needs articulated at community levels. These objectives are

1. To prepare community-based primary health care personnel to counsel, diagnose, and manage patients and families.

Training will focus on skills, knowledge, and attitudes required to provide appropriate services for people with AIDS. Training will also prepare health personnel to serve as community health educators, advising and counseling on steps necessary to stop the transmission of HIV.

2. To serve health personnel as a source of up-to-date clinical information and support for patient services.

We expect such services to be available for all health care providers in the ETC's geographic service area. The latest clinical and research information will be provided, and activities may extend to arranging for speakers for community hospital grand rounds. ETCs may also help providers to develop patient education resources such as pamphlets on prevention. ETCs should be an immediate source of help in answering questions on treatment protocols or particular patient-related problems. These centers will serve as a source for referrals for specialist treatment or psychosocial needs. Through such services, we hope to foster a system in which the educated primary care provider can work in tandem with consultants from the whole spectrum of health and social services.

3. To stimulate a multi-disciplinary approach to treatment of HIV-infected patients.

ETCs will provide education, training, information, and referral services to health professionals, including but not limited to physicians, dentists,

nurses, physician assistants, nurse practitioners, social workers, counselors, and psychologists. Through both education and the network of referrals, the centers will emulate models, already developed to a limited degree in some communities, of a true multi-discipline, multi-resource system of care.

4. To emphasize care in nonacute settings in both prevention and treatment.

Appropriate ambulatory care is cost-efficient and beneficial. It permits patients to continue a home life among friends and family and allows better allocation of more expensive acute care resources. As more therapeutic options become available, fewer AIDS patients will require lengthy hospital stays, and ambulatory or outpatient treatment will be the favored option.

5. To enhance provider sensitivity through education.

Providers will receive training in how to take appropriate patient histories that incorporate sexual and drug use histories and how to counsel patients effectively on the associated risk behaviors.

Provider training for migrant and community health centers. Coordination among the providers of various health and social services is critically important because it ensures cost savings through elimination of duplicate services and allows for better managed care for AIDS patients. HRSA is coordinating AIDS-related activities among its various service and resource programs. For example, its Bureau of Health Care Delivery and Assistance has developed guidance and technical assistance materials on the care and treatment of HIV infected persons for the staffs of the more than 600 community and migrant health centers that are supported by HRSA grants. These centers provide services to more than 5.5 million low-income, underserved people. As the AIDS epidemic moves from urban areas, we expect that these centers will become an even more valuable resource of primary medical and preventive care.

The Final Need

The medical and social needs of AIDS patients make enormous demands on our health care delivery system. As we learn to deal effectively with this epidemic, and work to close the gaps in our health care system which it has made more apparent, we can develop resources that might be devoted to all populations in need of health care.

Perhaps then, from this tragic epidemic will come an improved, more cost-effective, and compassionate system of health care for all our citizens.

References

1. Green, J., Singer, M., and Wintfeld, N.: The AIDS epidemic: a projection of its impact on hospitals, 1986-1991. Prepared for the Committee on a National Strategy for AIDS, Institute of Medicine, National Academy of Sciences (undated). Quoted in National Center for Health Services Research and Health Care Technology Assessment: Program Note: Selected bibliography on AIDS for health services research, September 1987, p. 65.
2. Health Resources and Services Administration: Report of the Intragovernmental Task Force: AIDS health care delivery. U.S. Government Printing Office, Washington, DC, January 1988.
3. Health Resources and Services Administration: Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families. DHHS Publication No. (HRS)-D-MC87-1. U.S. Government Printing Office, Washington, DC, 1987; (a) pp. 65-66; (b) p. 3.